



Parental concerns towards children and adolescents with epilepsy in Sri Lanka—Qualitative study



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ABSTRACT

Purpose: Social, cultural, psychological and many other factors significantly impact the lives of epileptic children and their families. Parental concerns towards their children are less known in south Asian children with epilepsy. We aimed to identify the parental concerns regarding their children and adolescents with epilepsy in Sri Lanka.

Methods: We carried out qualitative study in 3 districts of Sri Lanka, comprising 16 in-depth interviews with parents of children and adolescents with epilepsy and 3 focus group discussions with primary caregivers of epileptic children and key informants (schoolteachers, public health staffs). Content analysis of the interview data was performed.

Results: Parental concerns were spread among seven themes that emerged from the content analysis. These concerns were about the child's functioning in areas such as physical, behavioural, psychological and social, education, concerns related to anti-epileptic therapy and epilepsy as a disease. Parents were more concerned about their child's safety, educational achievements and future prospects in terms of employment and marriage. Unpredictability of seizures, fear of stigma and unawareness of epilepsy were the main reasons voiced by the parents for having such concerns. Increased concern and perception of vulnerability was seen among parents whose children had epilepsy and co-morbid illness.

Conclusions: Parental concerns towards their children and adolescents show a multidimensional construct. Unpredictability of seizures, fear of stigma and unawareness of epilepsy were identified as key influential factors in moulding the parental concerns.

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1. Introduction

Epilepsy is a chronic neurological disorder characterized by an episodic nature. Seizures alone often produce only a short spell of disruption of consciousness and function. However, the associated psychological, behavioural, social, educational and cultural factors create a significant impact on the lives of patients and their families [1]. Thus, epilepsy is described as a social stigma, with poor social prognosis; which sometimes can be worse than its clinical prognosis. Psychosocial issues are not confined to adults with epilepsy. They appear to start at a younger age and affect the

entire family [2]. Epilepsy occurring in the developing years of a child carries a greater potential to affect the quality of life negatively [1].

Health related quality of life (HRQL) is defined as an individual's subjective perception of the impact of health status, on physical, psychological, and social functioning [3]. This is often heavily influenced by the parent's attitudes and behavioural responses towards the child's illness [4]. Parental perception of epilepsy is likely to be influenced by culture and social beliefs. This aspect is poorly studied in the Asian region. There is no documentation of parental perception related to Sri Lankan children with epilepsy. In an era where epilepsy treatment goal is not just minimizing the seizures and adverse effects of drugs, it is important to understand the parental concerns towards their child with epilepsy to meet the goal of improving the quality of life successfully. This study aimed

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to identify the concerns of parents regarding their children and adolescents with epilepsy in Sri Lanka.

2. Methods

2.1. Approach

Qualitative study was chosen as it provides an effective methodology to investigate experiences from the perspectives of the individuals [5]. Besides, data generated in qualitative research are culturally specific, contextually rich and meaningful and provide in-depth exploration of issues that cannot be achieved through quantitative methods [5]. We conducted in-depth interviews to establish a deep understanding of what parents experienced in the given socio-cultural context and to identify their concerns regarding their children and adolescents with epilepsy.

To check the credibility of the gathered data, especially whether the parents overestimate their concerns related to social aspects such as stigma merely because they have a child with epilepsy or if it really exists in the society, we did data triangulation [6–9]. We chose to include individuals from the same social context who share the same norms and are aware of the customs in that context. We conducted focus group discussion (FGD) with key informants from the local areas such as group of schoolteachers and group of public health staff i.e. medical officer of health, public health nursing sister, public health midwives and child probation officers to validate the social aspects and a group of primary caregivers (parents, non-parent primary caregivers such as grandparents) of children and adolescents with epilepsy to validate data related to the impact of epilepsy on child, family, etc. to see if similar concerns emerge from these groups. In our study, FGDs were used as a form of methodological triangulation. FGD data were used to complement the in-depth interview data [8].

2.2. Setting and sampling strategy

Study was carried out in three out of the 25 districts (Ampara, Monaragala and Hambantota) in Sri Lanka. This three represent a multi-ethnic community in Sri Lanka. Ethical approval for this study was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Colombo.

Purposeful sampling technique was used to achieve maximum variation within the in-depth interviews and FGDs [10]. Sample size was not calculated prior to data collection. It was determined during the research process on the basis of theoretical saturation point. This is the point in data collection when new data gathered by conducting further interviews no longer bring additional insights to the research questions [5].

Parents of children and adolescents aged 0–18 years with epilepsy were identified from the paediatric and adult clinics in state hospitals in each district. We included them regardless of the type and duration of epilepsy. We also included parents of children with epilepsy and co-morbid illnesses such as cerebral palsy to study the complete spectrum of concerns related to epilepsy. Participants were contacted by phone or via public health midwife. All interviews were held in participants' homes.

FGDs were conducted at a common venue convenient to all participants such as community centre for the group of primary care givers and respective work places for other groups.

2.3. Data collection

Informed written consent was sought before conducting in-depth interviews and FGDs. Data were gathered using standard procedures for in-depth interviews and FGDs [5,11]. Primary

author conducted all interviews and FGDs using pre-tested, semi structured interviewer guide. Open-ended questions were asked from the parents to describe their experiences and concerns in 4 main topics i.e., impact of epilepsy on the child's development and adjustment, impact of epilepsy on the family, impact of the community and impact of disease (epilepsy) and its treatment in general. Key informants in FGDs were asked to describe the impact of community on patients and families with epilepsy (e.g. How people in this community regard children/adolescents with epilepsy? What are the common beliefs surrounding epilepsy in this community? Are there any difficulties for children/adolescents with epilepsy to live a normal life?) All interviews were conducted face-to-face in Tamil or Sinhala, the main dialects in the country. Interviews were audio-recorded and transcribed verbatim in the local language and later translated into English.

2.4. Analysis

Primary author analyzed the data manually by content analysis approach [12], which included the following steps—data cleaning, coding, categorization and theme development. To minimize bias in data analysis, 10% of data were double coded by an independent investigator who was not involved in the study. Variation in coding was discussed in a meeting to arrive at a consensus.

3. Results

Total of 16 in-depth interviews and 3 FGDs were conducted. Participant characteristics for in-depth interviews are given in Table 1 and composition of FGDs in Table 2.

Seven themes related to parental concerns emerged from the in-depth interview data analysis. Brief descriptions of these themes are presented here since it's difficult to report all of the qualitative data [12]. FGD data were exclusively used for validation purpose and had no effect in the development of themes with respect to parental concerns. We would like to add that the findings from FGDs were essentially the same as it was from the in-depth interviews and there was no new information gained from FGDs.

3.1. Concern about physical functioning

The interviews demonstrated that parents were concerned about epilepsy affecting their child's physical ability to function normally. It appears most of the parents were happy with the growth and development of their child although they often deemed epilepsy as a serious disease.

After this illness (seizure) she couldn't walk. We were scared thinking that she would never walk again... after taking the medicine, she started walking again... Children like this (with epilepsy) are like that... aren't they?. without walking and unable to speak isn't it? We never thought that she would be like what she is now. Even though we are worried that she got sick (seizure), we are happy that she's able to do everything now (mother of a 9-year-old girl).

Parents of children with epilepsy and co-morbid illnesses such as cerebral palsy/mental retardation were more concerned about the developmental delay especially when the child cannot perform day-to-day tasks without assistance.

Physical injuries due to fall during seizures was one of the reason for not allowing the child to be alone. *'We want to send her alone, but we only understand when she's going to get sick (seizure) and fall, others don't know this. When she goes to neighbour's house to play, I also go with her.'* (mother of 9-year-old girl)

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